DOCUMENT RESUME

ED 330 132 EC 300 102

AUTHOR Ripley, Suzanne
TITLE Doctors, Disabilities, and the Family.
INSTITUTION Interstate Research Associates, Inc., Washington, D.C.; National Information Center for Handicapped Children and Youth, Washington, DC.
SPONS AGENCY Special Education Programs (ED/OSERS), Washington, DC.
PUB DATE May 90
CONTRACT G0087C3051
NOTE 17p.
PUB TYPE Guides - Non-Classroom Use (055) -- Collected Works - Serials (022)
JOURNAL CIT A Parent's Guide; v1 n2 May 1990

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS American Indians; *Disabilities; Interdisciplinary Approach; Interpersonal Communication; Medical Care Evaluation; Medical Services; *Parent Responsibility; Parent Role; *Physician Patient Relationship; *Physicians; *Questioning Techniques

ABSTRACT

Intended for use by parents of children and youth with handicaps, this guide offers guidelines for choosing a physician and communicating with him/her concerning the needs of the handicapped child. The question-answer format addresses the following issues: how do families choose a doctor for their child?; what about the child who has a disability?; what exactly does a primary care physician do?; how do you find such a person?; what happens if you use a public health clinic?; what are Indian Health Services?; who can use Indian Health Services?; how do families interview doctors?; what should a family do before the first visit to the doctor?; what should you talk about?; how can doctors and schools work together?; what are the parent's responsibilities?; and how do you evaluate the situation? A list provides specific questions a parent might want to ask, grouped in the following categories: questions to ask on the phone when interviewing doctors; questions to ask when scheduling an appointment for your child; questions about an illness; questions about general check-ups and development; questions about medications; questions about tests; questions about referrals to specialists; questions about surgery; and questions about hospitalization. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED330132

A PARENT'S GUIDE

Doctors, Disabilities, and the Family

Volume I Number 2 May 1990

A Parent's Guide to Doctors, Disabilities, and the Family

by Suzanne Ripley

How do families choose a primary health care provider or pediatrician for their child? Specifically, how do families with a child who may have a disability and/or special health care need choose a doctor? How do families work with their pediatrician for the maximum benefit of their child, to locate appropriate specialists, correctly assess their child's needs, and work with the education system? These are questions many families ask. This paper will explore these questions and discuss some possible answers.

Q: How Do Families Choose a Doctor for their Child?

A: Choice of a doctor may vary depending on the size town you live in, whether you live in a rural area, whether you use a private doctor, health maintenance organization, group health organization, public health center, Indian Health Service, or clinic.

You may live in an area where there aren't many doctors to choose from. In such a situation, the primary care physician may be located in another town and serve as a specialist with whom you consult by phone and to whom reports can be mailed. This doctor can advise the family as well as the local pediatrician on evaluations, medications, and other specialists. Families may see their local pediatrician for all routine baby and child health needs but work in a team type situation with the primary care physician who may be a specialist with the University Affiliated Facility, at the state university medical school or at another major hospital either in the state or in another state. For children with rare syndromes or unique medical needs, a specialist may be located quite a distance from the family but still be actively involved in decision making.

The first step in obtaining medical assistance should be the identification and selection of a primary health care provider. This sounds simple

Compiled By:
The National Information Center for Children and Youth with Handicaps
Post Office Box 1492 Washington, DC 20013
703/893-6061 (LOCAL/VOICE); 703/893-8614 (TDD ONLY); or 800/999-5599 (TOLL FREE)

EC 300102

BEST COPY AVAILABLE

enough; yet, an article in Pediatrics, "First Step in Obtaining Child Health Care: Selecting a Physician," (Hickson, Steward, Altemeier, & Perrin, 1988) indicates that parents included in the study did not spend much time or energy selecting a doctor. According to its authors, this study is the first to evaluate the process of physician selection for children. The parents were asked how they selected their child's doctor and what factors were important in their decisions. Fifty-three percent of the families surveyed considered only two or three physicians in their decision; 34% considered only one. They also indicated that an average of only 1.2 sources of information were used in identifying and evaluating potential doctors. The sources most commonly used were talking to a neighbor or friend (44%) and discussing choices with another doctor (21%). Decisions were based primarily on one of three characteristics: communication skills (willingness to share decision making, warmth, concern), accessibility (return calls quickly, quick appointments), and quality of practice as determined by recommendations from friends and family.

Q: ***Are Families Satisfied With the Doctor They've Chosen?***

A: Parents surveyed in this study also were asked why their families changed pediatricians. The most frequently stated reason for changing doctors was the family's perception that the doctor was not managing a specific illness adequately. The second most frequently stated reason was that parents believed their child's doctor or office staff was rude or unconcerned. Third was that they objected to their physician's lack of interest in their child's behavior. The fact that more than 40% of parents who were dissatisfied with pediatricians expressed this complaint reinforces the notion that parents are concerned about psychosocial health, or that perhaps psychosocial health is not addressed adequately in our health system.

Q: ***What About the Child Who Has a Disability?***

A: All families have unique needs. The above study was conducted with families whose children were not identified as having any type of disability. For the child who may have chronic health problems, developmental disabilities, behavioral difficulties or physical disabilities the choice of a primary care doctor must be made with care and thought. The number of parents who were dissatisfied with their pediatrician's lack of interest in their child's behavior, coupled with parents who believed their child's doctor or office staff was insensitive or unconcerned, substantiate the need for extra thought and planning.

Relating to a child whose needs are distinct or unaccommodating can be difficult. Yet, a child needs to be able to communicate with his doctor as well as develop trust and rapport with him. In addition, the child should be comfortable with his medical needs and care. Even young children need to be able to talk with their doctor. Older children and teenagers need to have more involve-

ment in their medical decisions and concerns, and need to feel comfortable talking openly with a physician who understands them. Therefore, it is imperative that the doctor you select manage a two-way communication with the child, accept the child's unique behaviors and disability, look past such impediments, and treat the child with the same concern shown for other children.

Q: ***What Exactly Does a Primary Care Physician Do?***

A: The primary care physician is the medical doctor who coordinates the child's health care needs. This physician treats the whole child, is concerned about the child's health and development, can refer families to specialists and clinics, obtains developmental and psychological evaluations, and helps interpret the results of these tests. This primary care physician can help coordinate the variety of other medical needs by helping to avoid duplicate testing, distinguishing the absolutely necessary from the less important to cut down on discomfort for the child, recommending specialists who are comfortable with your child, and keeping records of all evaluations and their results.

Frequently, the primary care physician is the first professional parents turn to when they are concerned about their child's development. This is the person who can discuss tests, their potential value, the results and then develop a possible prognosis. Unfortunately, no doctor can be expected to know the answers to all your questions, but a physician should be able to openly acknowledge areas he knows less about and be able to say "I don't know," when that's the only answer. This can only be accomplished if the parents are comfortable with the physician, feel he/she is understanding of their unique concerns, and accepting of their child. In the same way, the physician must feel comfortable with the family and know family members are understanding of his/her role in the care of their child.

Q: ***How Do You Find Such a Person?***

A: Clearly, families with a special needs child will have a greater task before them in the doctor selection process than other families. While the survey we've referred to indicates that most families spend little energy choosing a physician, it is none the less an important matter which must be approached in a concerned and methodical manner.

As with all selection processes, the first step is to identify your needs. The following questions may help you pinpoint those needs. What is important to your family in dealing with medical needs? What do you expect? What do you think you need? In what ways are your child's needs different from other children's needs, that is, specifically how is your child unique? Do you need several doctors and therefore need each to be open to discussions with the others? Do you need a doctor more frequently than other families and therefore want someone close to home? Do you need a wheelchair accessible office?

Does your child have more complex medical needs than other children or is the major difficulty in the area of development and behavior?

It is important to understand that if your child's needs are significantly different from your neighbor's children, the neighbor's pediatrician may not be the best choice for your child. When seeking personal recommendations for a doctor for your child with disabilities, you may be more successful talking to families whose children are more like your own. Such families can be found in oganizations such as the United Cerebral Palsy, the Epilepsy Foundation, the Spina Bifida Association, Parent-to-Parent, EPICS, or the Learning Disabilities Association of America (formerly ACLD). Perhaps your child is still very young and you don't know other families in your area with children like yours. Families can find a lot of information in the phone book by contacting doctors listed as Developmental Pediatricians. If there are no such listings, contact a Pediatric Neurologist or child psychiatrist or call the Department of Pediatrics at the closest hospital and ask for the name(s) of Developmental Pediatricians. Another resource may be the state university medical school's Department of Pediatrics. If you usually get medical care from a clinic, group, Public Health Department or Indian Health Services, you may want to ask the head nurse there for suggestions. It is important to remember that if your medical expenses are covered by a particular service provider, referral to specialists may need to come through formal channels unless you will be covering all costs yourself.

When asking for a referral to a local pediatrician, there are several important steps. Be sure to request a referral rather than ask for a recommendation; it is difficult if not impossible for someone on the phone to recommend a doctor to someone he/she has never met. In this instance your choice of words is important. A referral is less formal and will net better results. Ask for several referrals if possible to allow you some choices and to place less responsibility on the person making the suggestions. You can say, "I have a child (age) who does not seem to be developing like other children his/her age. Do you see such children in your practice? Is this an area of interest for you? If not, can you refer me to a pediatrician whose special interest is children with possible developmental difficulties?" (A list of suggested questions is at the end of this article.) Be specific about your child's needs; if this is a child whose behavior is very difficult, be honest about this. After all, you are looking for a doctor who is accepting and comfortable with such conditions.

Q: ***What Happens if You Use a Public Health Clinic?***

A: Families using a clinic or public health facility also can arrange to see specialists. Speak either to the doctor who is seeing your child or to the nurse on duty. Discuss your child's needs and ask about the procedure for being referred for children's specialty services. You may be concerned that your child is not developing normally without knowing the specific needs. This too can

be discussed with the doctor or nurse. The names of specialty children's services and the process of assessing them may vary state to state, but basically, a public health clinic can refer a baby or child to one or more speciality clinics. Generally these clinics cover orthopedic needs, seizure disorders, neurological conditions, hearing loss and other special needs. The doctors at these clinics are usually specialists working on an honorary basis and payment is generally on a sliding scale from no payment up to whatever the family can afford to pay. A child who is referred to a speciality clinic would still be followed by the original or well-baby clinic for routine needs, shots, well baby visits, and common childhood illnesses.

In cases where a child may be referred for surgery or treatment at a hospital, the public health clinic should be able to help make arrangements. If the hospital to which the child is referred is not local, plans for transportation, lodging for the parent, and payment can be made.

Many of these services are available through Medicaid, WICC (Women, Infants, and Children's Care), local health department, and state Department of Health. ***Public Law 99-457, Part H, Handicapped Infants and Toddlers Program***, may also cover some of these needs, especially in the areas of developmental screenings, hearing and vision tests, therapy, and family information services. (For more information on PL 99-457, contact NICHCY.)

Q: *What are Indian Health Services?*

A: Health services for Alaskan natives and Indians who are enrolled in or direct descendants of recognized tribes may be available through the Indian Health Service (IHS). There are basically three types of services, direct care, contract care and urban programs. IHS clinics are located throughout the country, although they are not in every state. Their staff can either provide the medical care a child needs or refer the child to a specialist outside the Indian Health Service. There is no charge to the family for IHS services; the payment is made by the family's health insurance company, if they have one, by medicaid, if the family has applied and been found eligible for medicaid, or by the IHS. The people at IHS can discuss these options with you.

If a child requires specialized medical care not available through the local IHS clinic, then the doctor at IHS can refer the child to the needed specialist. The process for this referral is called Contract Care. This may be based on medical priorities to determine whether the patient should be seen immidiately or whether deferred services can be suggested. It may be useful for the family to confirm that the formal Contract Care referral has been made, to insure proper payment. The family should contact the Contract Health Service authorizing official in the service unit where your family is being seen. Contract Care referrals must come from IHS. Obviously a family can seek medical care at other facilities but then they must arrange payments for these services on their own; IHS will cover expenses only when they have authorized the referral.

In situations where the family must travel long distances to needed medical services, staff at the IHS clinic can help make travel arrangements. They may also be able to help with arrangements for overnight stays away from home.

Q: *Who Can Use Indian Health Services?*

A: There are several important points to keep in mind when using direct care Indian Health Service. First, the family must be eligible. Basically, the criteria are that the individuals are enrolled in a recognized tribe or can prove direct descendancy of a recognized tribe. The family must be in the IHS delivery area. There are situations in which a person may be living somewhere else, for instance a student attending a school away from home may require medical services, and be eligible for IHS.

Adopted and foster children of eligible Indian families, whether or not they are Indians themselves, can receive care through IHS until they reach the age of 19.

Contract Care services through IHS may have stricter eligibility requirements. Individuals using this service must meet residency requirements and have close social and economic ties to their tribe. There may be requirements for filing for medicaid too. Urban programs have distinct eligibility criteria too. If you are not sure if your family is eligible, check with your local IHS.

If you have questions or need help, you can call the closest IHS facility or phone Dr. Jerry Lyle at Indian Health Services at Maternal and Child Health in Rockville, Maryland. The number is (301) 443-1948.

Q: *How Do Families Interview Doctors?*

A: When you have your list of referrals, begin the process of "interviewing" the prospective doctors. Talking to doctors about their areas of interest is not uncommon; there is no reason to feel uncomfortable about such a process. Begin by phoning the physician's office. Ask to speak to the receptionist or nurse first and ask again if this doctor sees children like yours in his/her practice. If the answer is yes, or if the nurse seems positive about the doctor's interest in children like yours, ask for the doctor to give you a call. Doctors usually set aside some time each day to return calls; be sure to make it clear that this call will take a bit longer than most and that you would like him/her to phone when there is time to talk for about 5 or 10 minutes. Do this for each of the doctors on your referral list.

If your family receives medical care through a clinic, talk to the person in charge to learn how the public health department works with children who need in-depth medical attention. Find out what services are available, how to access them, who is the case manager or keeper of all the records, and the eligibility requirements for all of this. Ask what interagency relationships this clinic has with other health care providers in your state and with the education

department, when applicable. If the person you are asking does not know the answers to your questions, ask who on staff is familiar with your needs. If the person you are asking is too busy to talk to you, ask when you could come back or when he/she could phone you so you will have time to discuss your concerns. There are policies for public health clinics to work with other medical facilities to meet the needs of children with unique or chronic health care difficulties. You will need to keep asking questions until you find the person who can make these connections for you. By asking lots of questions, you can learn how to work effectively with your state's and county's public health service to provide all the specialized medical services your child may need.

Q: ***What Do You Say to a Doctor You've Never Met?***

A: When you speak to the doctor, again explain your child's unique needs and your family's expectations. Ask if children like yours are an area of interest to him/her. Ask the most important questions on your list of expectations for a pediatrician for your child. Does he/she have experience with children who have social or behavior difficulties? Does he/she feel comfortable working in a team type situation with other specialists, the family and schools? (A suggested list of questions is listed at the end of this article.) After you have asked these questions to all the doctors on your list, you may want to make an appointment to see the doctor whose responses were most positive and favorable. You will be the one who makes this judgement based on your wants and his/her responses to your questions, and general attitude to your needs. If you would like to first bring your child in for the doctor to examine, then ask if it is possible to arrange an appointment which possibly may last longer than usual. If your child has difficulty waiting and does not do well sitting in a doctor's office, schedule your appointment either first thing in the morning or as the first appointment after lunch. Appointments are made by the receptionist/secretary not the doctor, so be sure to let the receptionist know that your child will not be able to wait comfortably (or you will be uncomfortable controlling your child in a waiting room) and you will take the next available appointment which can guarantee little or no waiting, even if that means setting the appointment weeks in advance. Your stress level is important too, if you do not want to deal with an active child in a crowded doctor's office, then plan your visits in advance and avoid distressing situations.

In clinics there are also times which are less busy. If your child cannot comfortably sit in a clinic to wait for the doctor, talk to the nurse in charge and explain the problem. Ask what times of day are least busy. Frequently the very end of the day is the quietest, since many patients have already left and the staff is interested in finishing appointments for the day.

Q: ***What Should a Family Do Before the First Visit to the Doctor?***

A: This "new" doctor will need information about your child and his/her medical history. Before the first appointment, be sure all medical records are either

mailed or delivered to the doctor's office. It would be useful for these records to arrive at least a week before your visit so that the doctor has time to look them over.

If your child has already been seen by specialists, have these reports sent to the doctor too. If your child has educational assessments, send these along as well. The more the doctor knows about your child, the better able he/she is to discuss your concerns.

Requesting that medical records be sent to another doctor is routine. You should not feel uncomfortable requesting your child's records. If your child has already been seeing a doctor, it is always acceptable to request an additional opinion without insulting the first doctor.

You can phone or write to the first doctor's office and say, "I am interested in discussing my child's situation with another doctor to get additional opinions. Please send a copy of my child's records to Dr. (fill in the name) at (give the mailing address)."

You might also make a list of topics for discussion with the "new" doctor. Since many children are shy around a doctor, especially one they've never met before, you may need to bring up problems which the doctor cannot readily see. For instance, if you suspect your child may have a language delay, say so. Then the doctor can try to initiate more conversation from your child to better observe your concerns. If you are worried about possible developmental delays, make a list of things your child does or doesn't do to give the doctor concrete examples of behavior he/she may not be able to observe in the office. If you would like a referral for a hearing screening or vision tests, be sure to mention this. Doctors can conduct preliminary visual, hearing and speech screenings in their offices to help to determine if a specialist is needed.

Q: ***What Should You Look For When You Get to the Doctor's Office?***

A: Look around. Is this office "child proof"? Are there toys for your child to play with? Are there many things he/she should not touch, climb or get into? Can you let your child move around in this office without undue restraint? Are well children separated from children who may have contagious illnesses?

How are the office staff? Do they seem open and friendly, or do you feel out of place here? Are the nurses who weigh the child, conduct eye exams and perform some of the examination functions comfortable with your child? Are they pleasant to you? Are they supportive of your needs?

Does your child seem comfortable, or at least as comfortable as any child feels in a doctor's office? If he/she is frightened, is the staff warm and reassuring?

After the doctor has examined your child, you might ask if the nurse or receptionist could take the child out of the room for a few minutes so you can talk to the doctor alone. Children who are very active can make conversation difficult for both you and the doctor. If this is not possible, ask if the doctor can phone you later in the day to discuss your child and pick a time when you can talk on the phone uninterrupted.

Q: ***What Should You Talk About?***

A: Remember that many doctors may not have had formal training or experience in any types of disabilities, developmental delays, or family stress. There may be important cultural differences which you may need to clarify. You may need to do a bit of teaching yourself and explain your situation as precisely as possible. Try to be as unemotional as possible; professionals will discuss matters with parents who seem in control of the situation better than with parents who get overly emotional.

It would be useful to make out a list of your questions. This way, you will not waste each other's time and you will not forget any of the points you want to ask about.

If you have a school-age child who is having some difficulties in school, or who may have some special needs in school, remember that this is another area with which many doctors are unfamiliar. Just as you are uncomfortable with doctors who use many medical terms you do not clearly understand, so doctors can be uncomfortable with education jargon. Explain your child's educational needs and placement clearly. Doctors can make specific recommendations to schools, so talk about concerns you have with your child's education. Therapies, such as speech therapy, occupational or physical therapy, can be recommended by the pediatrician. Referrals to a specialist may also be in order. Some children require that medications be given during school hours or require special health care considerations. Perhaps the school nurse, therapist, teacher, counselor, principal or aide would like the opportunity to talk to the doctor; ask if that would be possible.

If you just want time to talk over your concerns about your child's overall development, say so and arrange for a time when both you and the doctor can discuss your questions at leisure. It may be a good idea to arrange a time when both parents (or primary caretakers), siblings, or the whole family can get together. If you state your needs clearly, then the doctor is better able to arrange appointments which will serve these needs.

Q: ***How Can Doctors and Schools Work Together?***

A: Some children's disabilities may appear to have no more medical needs than other children. They may have processing problems and other learning prob-

lems which can sometimes be linked to sensory conditions which interfere with school functioning, such as middle ear infections. Medical conditions such as meningitis, head trauma, or serious ear infections can put a child at risk of learning disabilities. These are issues you may find important to talk about. In doing so, you may wish to work towards establishing a relationship between the doctor and school. You can help develop this sort of relationship by sharing school report cards, therapy arrangements, evaluations and conference reports with your child's doctor. It may also be useful to share ideas for learning and/or behavior that worked; the more the doctor knows about your child and other children with similar difficulties, the better able he/she is to help.

Other children may have special medical needs which lead to "hidden" disabilities and may require accommodations in school through the special education system. The nurse may need to be aware of children with diabetes or epilepsy, school staff may need to exercise some safety precautions with students who have spina bifida or who are medically fragile, some children may require certain dietary restrictions, and still others with physical disabilities may need accommdations in some classes. Students may require related services, resource room help, or may need special transportation. For children who are eligible for special education services under "other health impaired" categories, the doctor's reports are vitally important. In all these areas, your primary care physician can be an important member of the school team.

It may also be useful to share the doctor's suggestions with school staff, therapists, or early intervention team. Let these people know any medical information which may be important to them, certainly any changes in medication or medical conditions. If a child is recovering from an illness or has special health care needs, including stress, discuss this with the school staff as well as the doctor. You are working on team building, and all team members need to be kept informed and up-to-date. Some medical conditions can be related to school stress, such as frequent stomach aches, headaches, or skin irritations. Such anxiety related conditions may require changes in school programs or expectations. Sometimes difficulty in school can lead to psychosomatic complaints which both the doctor and the educators need to be aware of and discuss.

Q: ***What are the Parents' Responsibilities?***

A: Families also have medical responsibilities. You, after all, are the ones who will carry out the doctor's recommendations. You are the primary caretaker of your child and to do so, you need to be sure you understand the doctor's instructions.

Take a notebook with you so you can write down any instructions, names of specialists, or suggestions and observations. If the doctor prescribes a medication, be sure you understand how it is to be given and when. Should this be taken before, after or during meals? Does this medication have to be given at

school or can it wait an extra hour until your child comes home? Are there any side effects you need to watch out for? (More questions are listed at the end of this article.)

If the doctor refers you to a specialist or requests tests be done, ask how this test or referral will make a difference in the treatment of your child. What information is needed to help this child and how will this referral supply that? Ask the doctor to help coordinate this referral and/or tests so they will be conducted efficiently and will cause as little trauma for your child as possible. For instance, if blood tests are necessary, can all be done at one place so blood will only need to be drawn one time? The object is to get the maximum information with the minimum discomfort to your child.

For families using clinics, case management may be a difficulty. While one role of a primary care physician is that of case manager or overseer of all medical and medically related services, you and/or your family may need to become the case manager if your primary care is handled by a clinic. In some instances, case management may be available through the nursing staff of the public health clinic or arrangements may be made by them. Again, this service varies in each locality and is dependent upon certain criteria. Some clinics have social workers on staff who can work with families to help coordinate services. If your child is an infant or toddler (birth to 3 years), Public Law 99-457, Part H, Handicapped Infant's and Toddler's Program, may be helpful in this area. You may find it useful to contact the early intervention representative in your state or local area, or the Bureau of Indian Affairs if you live on a reservation. In some states, this information can be found by calling your local school, or the Special Education Director, or by calling the local Health Department, listed in your telephone book. If you would like more information about early intervention services available under Public Law 99-457, you can also contact NICHCY.

Public Health Departments, IHS, and clinics are organized differently in different areas, however, all can provide medical records to you and to anyone else you ask them to send the records to. If you are involved with several specialty clinics, doctors and/or therapists, be sure one is getting reports from all the others. This is important so tests aren't unnecessarily repeated and so medications are monitored. In general, the local clinic who first saw your child and who referred you to the specialists would be the clinic to keep all the records. If the doctor at the hospital where your child was born is the one who originally referred you, you will need to ask if this doctor is now the primary care physician or if you need to visit your local clinic and establish yourself there. The important thing is to be sure someone has all records in a single location and can provide needed information to specialists and any new doctor seeing the child. This person may be you.

Remember that it is often difficult for a pediatrician to say, "I don't know."

You should ask all the questions you need to feel comfortable that you understand all recommendations and diagnoses, but you need to also be aware that not all of your questions can be answered. In a team effort, everyone needs to take his/her turn listening and understanding.

Q: *How Do You Evaluate the Situation?*

A: Evaluating the situation is an ongoing process involving team effort. Families see their child most, then schools (if the child is school age), and then the therapist(s); a doctor sees the child infrequently. Therefore, families are the primary evaluators of their child's progress, with the reports of schools, therapists and others. Children frequently behave differently in school and at home. It is important for everyone to communicate openly. Teachers and therapists report regularly; if you feel you need more information from school, you can arrange to meet with your child's teacher(s) and/or therapist(s) to discuss your concerns. Information from the family/school team can then be presented to the doctor, if appropriate, and he/she can join the team for some decisions or suggestions. Since the doctor is the only team member who has no opportunity to observe your child "in action," you must report all relevant information accurately.

Evaluation of the doctor or clinic is a parent responsibility. With the list of needs discussed earlier in this article, you can develop your own criteria of satisfaction. Establishing a good partnership with your child's doctor is the overall goal. This will take some time on both parts. You and your child's doctor should have mutual understanding of needs, schedules, perceptions of emergencies and non-emergencies, etc. It is usually worthwhile to work on your relationship with your child's doctor, discuss any concerns or specific needs you may have, and to change doctors only if you feel that he/she is unresponsive to your child.

To Summarize...

Your child may be seen by several doctors, clinics, and hospitals. Ultimately you, his/her family, are the case managers of your child's services. Your case manager duties are likely to include choosing a pediatrician, developing a relationship with him/her, evaluating the situation, and maintaining any records that result from the visits. Detailed record keeping is a vital part of your responsibilities. While the primary care physician and/or tertiary physician or clinic will maintain files for their records, you should maintain your home files. Your home files could be as simple as a box full of medical records or as sophisticated as you choose to have it. Most importantly, good communication and rapport among your child's team—you, your child if appropriate, primary health care provider, early intervention team, school personnel—should lead to quality care for your child.

QUESTIONS YOU MIGHT WANT TO ASK BEFORE THE DOCTOR HAS SEEN YOUR CHILD:

Questions to ask on the phone when interviewing doctors.

1. Do you see children with disabilities in your practice?
2. Do you have experience with children who have (describe your child's disability)?
3. Would you be comfortable working in a medical team situation with other doctors who will be seeing my child?
4. Can you schedule extra long appointments?
5. Who sees your patients when you are not available?
6. Which hospital so you use for patients who require hospitalization or hospital tests?
7. What are the facilities of this hospital for children and families like mine? If my child were hospitalized, would I be allowed to stay with him/her?
8. After you've examined my child, can you arrange for one of your staff to watch him/her for a few minutes so we can talk alone?
9. Would there be any additional charges for any of these arrangements?

Questions to ask when scheduling an appointment for your child.

1. I will be needing a longer appointment than most families. Can we schedule a time when we can have a double appointment?
2. My child has difficulty waiting patiently, is the first appointment of the morning available or one right after lunch break?
3. If you don't make appointments, what times of day or which days of the week are least busy?

QUESTIONS TO ASK WHEN THE DOCTOR HAS SEEN YOUR CHILD:

Questions about an illness:

1. Can you make a diagnosis at this time?
2. Would you recommend a second opinion or a specialist for this illness?
3. Should anything be done immediately? What should we be doing over the next few days? Are there any long term needs/concerns?
4. When will the child begin to feel better? How long does this illness usually last?

5. Are there any symptoms I should be aware of to monitor this illness? What are the indications that he/she is getting better? What are the indications of any complication or worsening?
6. If I do notice any signs of complications, how can I contact you after office hours? In an emergency, whom should I call?
7. When can he/she go back to school? Are there any special precautions which the school should be aware of?

Questions about general check-ups and development:

1. Is he/she within the range of normal height and weight for his/her age? Is he/she growing at a normal rate?
2. Is he/she developing normally in the areas of physical abilities, speech, vision and cognitive development?
3. What are the age ranges typically during which children develop these abilities? Am I right to be concerned at this time? When should I become concerned?
4. Do you think some developmental screenings should be done at this time? Do you administer any of these tests yourself as part of the regular check-up? (If the answer is no, you may want to have the doctor write a report indicating a concern over development in a particular area which you can send to the school staff working with your child to request that they test your child or arrange for appropriate testing. If your child is not school age, you may request these results be sent to the school system to request early intervention screening.)
5. What are the next developmental stages we should be watching for? What can we do to help our child?
6. Should we be consulting with the early intervention program and/or therapists for our child? Will you collaborate with the school by sending copies of your evaluations or writing a report specifying my child's delays which I can use in talking to the local school system?
7. Can I give the school or early intervention team your phone number so they can call if they have any questions?
8. Do you think we should be consulting with any other specialists at this time? If yes, what are your recommendations? Can you refer us?

Questions about medications:

1. When should I give this medication?
2. When the prescription says "three times a day" does that mean every 8 hours including during the night, or three times during the daytime?

3. When my child goes back to school, will he need to take this medicine during school hours or can it wait until he gets home at (time)?
4. Should the child take this medication before, during or after meals?
5. Are there any foods which should not be mixed with this medication?
6. How long should he take this? Should he finish the bottle or stop when the symptoms go away?
7. (If your child has other medications he is currently taking) My child is currently taking (medication). Can he take this medicine at the same time?
8. Are there any possible side effects or allergic reactions I should be aware of? How will I recognize them? What should I do if I think he/she is having a reaction?
9. Does this medicine need to be stored at a special temperature, that is, does it go bad if the medicine gets too hot or too cold?

Questions about tests:

1. What do you expect to learn from these tests?
2. Have these tests been given to my child before? Can we coordinate any of the earlier results with these?
3. Does the school or public health clinic also do these tests? Is there any reason not to have them done there to save on expenses?
4. How long will these tests take and what is involved in them?
5. Is there anything I should tell my child about these tests which will help prepare him?
6. Can he eat before coming?
7. Are there any precautions I should take either before or after these tests?

Questions to ask about referrals to specialists:

1. Specifically, why is this referral being made? Is this a second opinion or are we seeing the specialist for a diagnosis?
2. Are there records I should take with me or will they be sent in advance?
3. Is this specialist comfortable with children like mine? Has he/she been fully informed about my child's disability or would it be useful for me to give him a call?
4. Who will get the reports of this evaluation? Who will be interpreting them? Who will be discussing these reports with me?
5. What are this specialist's rates? Can arrangements be made to help cover these expenses?

Questions to be asked about surgery:

1. What exactly will this surgery do or allow my child to do?
2. What are the consequences of not doing it?
3. Would there be any advantage in waiting to see if the situation improves?
4. How long will my child be in the hospital?
5. How long will it take my child to fully recover from this surgery?
6. Will we need any special equipment or help at home when he's released?
7. What are the possible complications or side effects?
8. Should we get a second opinion?
9. Do you think any additional surgery will be necessary?

Questions about hospitalization:

1. Can you estimate the length of my child's stay in the hospital?
2. Who will be the attending doctors?
3. Can I stay with him overnight?
4. Is there any information I can give him now to prepare him for this?
5. When is check-in time?
6. Does the hospital have a program for children explaining about hospitals which would be helpful for my child?
7. Will this be covered by my insurance?

REFERENCES

Hickson, G. B., Stewart, D. W., Altemeier, W. A., & Perrin, J. M. (1988). First step in obtaining child health care: Selecting a physician. *Pediatrics, 81*, 333-338.

This document was developed by Interstate Research Associates, Inc., pursuant to Cooperative Agreement #G0087C3051 with the Office of Special Education Programs of the U.S. Department of Education. The contents of this document do not necessarily reflect the views or policies of the Department of Education, nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Government. This information is in the public domain unless otherwise indicated. Readers are encouraged to copy and share it, but please credit the National Information Center for Children and Youth with Handicaps.